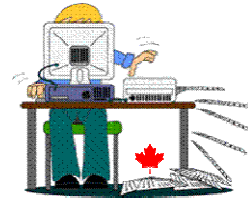


Media Watch...

is distributed weekly to my colleagues who are active or have a special interest in **hospice, palliative care** and **end-of-life issues** – to help keep them abreast of current, emerging and related issues, and to also inform discussion and to encourage further inquiry and research.

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Compilation of Media Watch 2008, 2009, 2010, 2011, 2012 ©

Compiled & Annotated by Barry R. Ashpole

Critical review of the literature: Scroll down to [Specialist Publications](#) and "Enhancing patient-professional communication about end-of-life issues in life-limiting conditions," (p.9), published in the *Journal of Pain & Symptom Management*.

Canada

Most Canadians have no written plan for end-of-life care, poll finds

ONTARIO | *Ottawa Citizen* – 26 July 2012 – Rather than ever lose his ability to think, remember or recognize his wife and children, Dr. Daren Heyland would sooner be dead. The critical care doctor and professor of medicine at Queen's University also states in his personal directive – a legal document that set out the treatments he would and would not want should he ever lose the capacity to speak for himself – that he would rather die than be left dependent on others to feed, dress, bathe or otherwise provide total care for him. Too many times Heyland has stood at the foot of a patient's bed in the intensive care unit and thought to himself: I never want to die this way. Death is inescapable, the "singular inevitability" for all of us. Yet the majority of Canadians – 80% – do not have a written plan about what life-prolonging treatments they would accept or reject at the end of life, and fewer than half have discussed the issue with their families, according to a recent Ipsos-Reid national poll. <http://www.ottawacitizen.com/health/Most+Canadians+have+written+plan+life+care+poll+finds/6996749/story.html>

Extract from *Ottawa Citizen* report

Too frequently, advance directives don't reach the people who ultimately will have to execute them. The recent poll showed that only nine per cent had discussed their wishes with their doctor. People also change their minds. B.C. palliative care expert Dr. Romyne Gallagher remembers one patient who had a stroke but recovered with some mild disability. He told his family that if he ever had another stroke they were not to do anything to keep him alive. He had a second stroke a few years later. He was unable to speak and had trouble swallowing. The medical team suggested a feeding tube. "The family said, 'Absolutely not, because he told us that this (allowing him to die) was what he wanted,'" Gallagher recalls. The man couldn't talk, but he could write, so Gallagher went to him and asked: "This is what we're thinking of. You're not eating and your family says you don't want anything to prolong your life. What are you thinking?" "Different now," he wrote.

N.B. In Ontario, wishes regarding end-of-life care expressed verbally can override previously written wishes, underlining the critical importance of ongoing communication and dialogue. *BRA*

Hospice gets approval

ONTARIO | *Owen Sound Times* – 25 July 2012 – In a unanimous decision, the South-west LHIN [Local Health Integration Network] board approved a motion that paves the way for a hospice, outreach and wellness model for palliative care in Grey-Bruce – the first ever for the region. The volunteer group has fought vigorously and passionately for a hospice over the last few years, particularly in the last several months when it appeared the LHIN board was about to approve a consultant's report that called for an outreach model only. A smaller scale version of the hospice is expected to be operating by winter. Four beds will open temporarily in a retirement residence, then up to six, before a 10-bed stand-alone hospice is built. <http://www.owensoundsuntimes.com/2012/07/25/hospice-gets-approval>

porarily in a retirement residence, then up to six, before a 10-bed stand-alone hospice is built. <http://www.owensoundsuntimes.com/2012/07/25/hospice-gets-approval>

Specialist Publications

Of particular interest:

'Palliative care training substandard' (p.8), published in the *Canadian Medical Association Journal*.

Noted in Media Watch, 18 June 2012:

- ONTARIO | *Sudbury Star* (OpEd) – 16 June 2012 – **'LHIN [Local Health Integration Network] plays games with rural region.'** <http://www.thesudburystar.com/ArticleDisplay.aspx?e=3586266>

Consciousness in vegetative patients

MRI Communication

MONOLITH | Online interview – 18 July 2012 – Professor Adrian Owen demonstrates a burning enthusiasm for his research and empathy with his patients, which is nothing short of admirable. He has spent the last 15 years attempting to detect consciousness in vegetative patients via functional neuroimaging. While much of his work involves using MRI technology, since relocating to Canada in 2011, newer EEG technology has also become a factor. MRI technology senses brain activity via changes in blood flow, while EEG detects changes in activity by measuring voltage fluctuations across the scalp. Owen discovered in 2006 that when humans imagine performing certain activities ... the brain activity produces specific patterns on imaging technology. Extensive experimentation enabled Owen and his team to communicate with patients in vegetative states. They would accurately respond to any number of "yes" or "no" questions by imagining certain tasks: playing tennis for "yes," navigating themselves through a house for "no." While many contenders of his work were unwilling to believe that it were possible for these previously-considered empty husks to house fully conscious human-beings, the fact that Owen had successfully communicated with these people forced many to reconsider the possibility. <http://www.monolithmagazine.co.uk/gallery/adrian-owen-mri-communication>

Extract from the *Monolith* article

It helps us to clarify the diagnosis and in some cases it has enabled us to communicate with patients for the first time since the injury. The more we know about these patients and the more that we can understand about how to diagnose them properly, the more likely it is that we will find solutions to some of their problems. Moreover, if we ignore them and pretend that they do not exist then science will not progress.

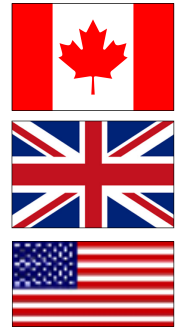
Noted in Media Watch, 1 November 2010:

- ONTARIO | *Globe & Mail* – 29 October 2010 – **'Vegetative patients may be aware, newly-recruited researcher says.'** <http://www.theglobeandmail.com/news/national/vegetative-patients-may-be-aware-newly-recruited-researcher-says/article1779227/>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- **ANGUS REID OPINION POLL | Online posting – 26 July 2012 – 'Canadians and Britons would allow euthanasia under some conditions.'** Canadians and Britons are more likely to voice support for doctor-assisted suicide than Americans, a new Angus Reid Public Opinion poll has found. In the online survey of representative national samples, 80% of respondents in Canada and 77% in Britain support allowing a doctor to – at the request of a competent, fully-informed, terminally ill patient – assist the patient in ending his or her life. The level of support for this notion is lower in the U.S., at 56%. While three-in-four Britons and Canadians (76% and 75% respectively) believe doctor-assisted suicide should be allowed, but only under specific circumstances, just half of Americans (50%) concur. In fact, three-in-ten respondents in the U.S. (29%) believe doctor-assisted suicide should never be allowed, compared to 10% in Canada and nine per cent in Britain. <http://www.angus-reid.com/polls/45951/canadians-and-britons-would-allow-euthanasia-under-some-conditions/>



U.S.A.

Local program educates minorities on hospice care

PENNSYLVANIA | *Pittsburgh Post-Gazette* – 29 July 2012 – A recent study found minority patients with heart failure were 20% less likely to use hospice care than whites.¹ The research ... would come as no surprise to the Rev. B. De Neice Welch, pastor of Bidwell United Presbyterian Church, North Side, and coordinator of Transitions. Bidwell Presbyterian partnered with Family Hospice and Palliative Care and the Northside Christian Health Center in February 2011 to create Transitions for just that reason, in hopes of increasing understanding of, and access to, hospice care among African-Americans in the greater North Side community. At the time, Family Hospice's database research showed that less than 5% of patients served annually were African-American. <http://www.post-gazette.com/stories/news/health/local-program-educates-minorities-on-hospice-care-646770/>

1. 'Racial differences in hospice use and patterns of care after enrollment in hospice among Medicare beneficiaries with heart failure,' *American Heart Journal*, 2012;163(6):987-993 (noted in Media Watch, 25 June 2012).. [http://www.ahjonline.com/article/S0002-8703\(12\)00171-8/abstract](http://www.ahjonline.com/article/S0002-8703(12)00171-8/abstract)

A move to increase hospice care

CONNECTICUT | *Stamford Advocate* – 25 July 2012 – Years of efforts to expand hospice care services in the state of Connecticut were rewarded when a legislative committee approved a new set of regulations governing hospice facilities. The new standards will make it possible for new hospices to be created throughout the state. Currently, families of terminally ill loved ones who desire hospice service must travel to one of two facilities in the state, in Branford and Waterbury, effectively eliminating the option for many Connecticut residents. The lack of availability is sadly ironic, given that the method of care was virtually invented here in 1974 at the Connecticut Hospice in Branford. <http://www.stamfordadvocate.com/news/article/A-move-to-increase-hospice-care-3735389.php>

[Media Watch posted on Palliative Care Network-e Website](#)

Palliative Care Network-e (PCN-e) promotes education amongst health care providers in places around the world where the knowledge gap may be wider than the technology gap ... to foster teaching and interaction, and the exchange of ideas, information and materials. <http://www.pcn-e.com/community/pg/file/owner/MediaWatch>

Catholic leaders warn against use of Physician Orders for Life-Sustaining Treatment

WISCONSIN | *The Compass* – 25 July 2012 – The Catholic bishops of Wisconsin recently expressed concern for upholding the dignity of human life in a statement warning against the use of Physician (or Provider) Orders for Life-Sustaining Treatment (POLST).^{1,2} POLST is a preset form that establishes medical orders to withhold or administer treatments. When signed by certain designated health care professionals, the form dictates whether to withhold or administer treatments such as cardiopulmonary resuscitation (CPR), antibiotics, or nutrition and hydration. The bishops said that the use of a POLST has grave implications for human dignity. The POLST form "presents options for treatments as if they were morally neutral. In fact, they are not. Because we cannot predict the future, it is difficult to determine in advance whether specific medical treatments, from an ethical perspective, are absolutely necessary or optional." The bishops noted that a POLST "oversimplifies these decisions and bears the real risk that an indication may be made on it to withhold a treatment that, in particular circumstances, might be an act of euthanasia."
<http://www.thecompassnews.org/news/local/3474-wisconsin-bishops-issue-statement-on-life-sustaining-treatment.html>

1. 'Physician Orders for Life-Sustaining Treatment,' Center for Ethics in Health Care, Oregon Health & Science University. <http://www.ohsu.edu/polst/programs/documents/POLST.2011.BWsmapple.pdf>
2. 'POLST registry do-not-resuscitate orders...,' *Journal of the American Medical Association*, 2011;307(1):34-35 (noted in Media Watch, 9 January 2012). <http://jama.ama-assn.org/content/307/1/34.2.extract?sid=c0d14c2c-00fa-4759-adc7-9469ac68565d>

Of related interest:

- NEBRASKA | *Lincoln Journal Star* – 27 July 2012 – '**End-of-life conversations needed, survey finds.**' The results of the 2011 Nebraska End-of-Life Survey, conducted by the Nebraska Hospice and Palliative Care Association, found that 70% of Nebraskans said they want their doctors to discuss their end-of-life care options, yet only 21% of Nebraskans had heard about hospice care from a doctor. http://journalstar.com/lifestyles/health-med-fit/health/end-of-life-conversations-needed-survey-finds/article_0d44445f-7ece-52a3-829c-1c42250efb42.html?comment_form=true

Does palliative care belong in the ER?

NEW YORK | Reuters – 24 July 2012 – Hospital administrators tend to agree that it's a good idea to have emergency departments offer palliative care... according to a new study.¹ But one of the biggest barriers to getting palliative care in the ER is the physicians. There's a stigma that palliative care is the same as end of life care, the same as hospice," said Dr. Corita Grudzen, the lead author of the study and an assistant professor in the department of emergency medicine at Mount Sinai Medical School. <http://www.chicagotribune.com/health/sns-rt-us-hospital-carebre86n187-20120724,0,6928352.story>

1. 'Hospital administrators' views on barriers and opportunities to delivering palliative care in the emergency department,' *Annals of Emergency Medicine*, 9 July 2012 (noted in Media Watch, 16 July 2012). [http://www.annemergmed.com/article/S0196-0644\(12\)00609-9/abstract](http://www.annemergmed.com/article/S0196-0644(12)00609-9/abstract)

Ethics and health care: Rethinking end-of-life care

WASHINGTON DC | The Heritage Foundation Center for Policy Innovation Discussion Paper – 24 July 2012 – America is undergoing a demographic revolution, with a rapidly aging population blessed with greater longevity. While this is a triumph of modern medicine, it also presents an unprecedented ethical and fiscal challenge for individuals, families, medical professionals, and policy-makers. In particular, Americans need to think carefully about care at the end of life. How should we think about life and death itself, the role of family and religion, and the duties of medical professionals and the use of advanced technology in the provision of end-of-life care? What is the role of freedom and personal responsibility?
<http://www.heritage.org/research/reports/2012/07/ethics-and-health-care-rethinking-end-of-life-care>

"outpatient palliative care"

Relief at the door: Palliative care improves lives and eases the cost of dying

CALIFORNIA | *Tri-Valley Times* (Walnut Creek) – 22 July 2012 – Marilyn Cronin was too sick to live. But she wasn't ready to die. So she curled up on the sofa of her Soquel mobile home, next to a bucket for vomit, and cried. Suffering from liver failure and lung disease – suspended between health and death – she braced herself for the next hospitalization, then another, and perhaps still others, until the last one, when her suffering would end. Then, unexpectedly, relief arrived: A cheerful nurse practitioner with a starchy British accent pushed open the mobile home door and pulled up a chair. For two hours, Karen Gossage just listened. Then the two women mapped out a plan: Which medicines might help. Where to get a walker. How to manage symptoms at home to prevent a midnight rush to the emergency room. Who would help her at the end. What was extraordinary was not just the thoughtfulness of the conversation, but its rarity – and, if replicated, how profoundly it could alter modern medicine. Simple steps to ease suffering, and save money, are the subject of this installment in our reporting on the emotional and financial cost of dying. This seemingly simple, yet pioneering program – known as "outpatient palliative care" – is part of an experiment sponsored by the Palo Alto Medical Foundation, soon to expand throughout much of the Bay Area. http://www.contracostatimes.com/tri-valley-times/ci_21122925

Noted In Media Watch, 17 October 2011:

- *ARCHIVES OF INTERNAL MEDICINE* | Online article – 10 October 2011 – '**Prevalence and characteristics of outpatient palliative care services in California.**' <http://archinte.ama-assn.org/cgi/content/full/archinternmed.2011.469>

Noted in Media Watch, 30 August 2010:

- *NURSING TIMES* (U.K.) | Online report – 29 August 2010 – '**Developing a nurse led hospice outpatient clinic to improve palliative care services.**' <http://www.nursingtimes.net/nursing-practice-clinical-research/clinical-subjects/palliative-care/developing-a-nurse-led-hospice-outpatient-clinic-to-improve-palliative-care-services/5018762.article>

International

Australian Senate Inquiry

A good death should be the norm

AUSTRALIA | *Sydney Morning Herald* – 28 July 2012 – If your elderly parent or beloved spouse became so seriously ill she was unlikely to recover, where would you like her to spend her last weeks or days? Most people want to die at home. But in Australia it is harder than it should be to achieve the good death – at home, pain free, and surrounded by loved ones. About 70% of deaths, according to some experts, occur in hospital. And while it should be possible to achieve a good death in hospital, that is not always the case. The country's palliative care services, which provide care to people with life-limiting illnesses – whether at home or in hospital – are underfunded, over stretched and patchily provided. A Senate inquiry is looking into their deficiencies. <http://www.smh.com.au/opinion/politics/a-good-death-should-be-the-norm-20120727-22z6s.html>

- *The Australian* – 26 July 2012 – '**Sick take palliative care over treatment.**' With many central Australian residents forced to travel to Alice Springs to seek medical help for kidney failure, some were leaving it too late or simply choosing to die at home rather than face distances of up to 1000km and time away from family. <http://www.theaustralian.com.au/national-affairs/health/sick-take-palliative-care-over-treatment/story-fn59nokw-1226435192319>

Irish Childhood Bereavement Network

New network to support bereaved children

IRELAND | *Irish Times* (Dublin) – 24 July 2012 – Some 3,360 Irish 16-year-olds [in 2011] may have experienced the death of one or both parents, a new study has estimated. The study ... also estimated that between 36,000 and 60,000 children in Ireland could have experienced significant bereavement. It was released to coincide with the setting up of the Irish Childhood Bereavement Network [ICBNetwork],¹ which will act as a hub for professionals and organisations working with bereaved children. The report identified weaknesses in the system including fragmented services, longer waiting lists for more complex bereavement support, and the lack of a services directory or forum to exchange knowledge and ideas. <http://www.irishtimes.com/newspaper/ireland/2012/0724/1224320710789.html>

1. ICBNetwork: Scroll down to 'Minister Frances Fitzgerald launches the Irish Childhood Bereavement Network' and 'Open publication' <http://irishchildhoodbereavementnetwork.blogspot.ie/>.

'Advance refusal' cards for patients fearing 'death pathway'

U.K. | *Daily Telegraph* – 24 July 2012 – Terminally ill patients are being issued with special cards warning doctors not to place them on a controversial "death pathway" amid fears the practice is becoming routine. The "advance refusal" notices operate like an organ donor card, enabling people approaching the end of their life to make their wishes clear to while they still have capacity. It comes amid a growing backlash against overuse of the 'Liverpool Care Pathway,' which allows medical staff to withhold fluid and drugs from a patient while they are heavily sedated, actively speeding their end. Supporters of the technique say that it is the kindest way of letting people slip away rather than die in pain. But leading doctors have voiced fears that hospitals are hastening the deaths of elderly patients to cut costs and free up bed space amid claims it has become a "standard" alternative to euthanasia. The number of patients put on the pathway has risen sharply in recent years... <http://www.telegraph.co.uk/health/elderhealth/9420794/Advance-refusal-cards-for-patients-fearing-death-pathway.html>

Noted in Media Watch, 9 July 2012:

- U.K. | *Daily Telegraph* – 8 July 2012 – **'Hospitals 'letting patients die to save money.'** Tens of thousands of patients with terminal illnesses are placed on a "death pathway" to help end their lives every year. <http://www.telegraph.co.uk/health/healthnews/9385674/Hospitals-letting-patients-die-to-save-money.html>

Noted in Media Watch, 23 April 2012:

- *JOURNAL OF PALLIATIVE MEDICINE* | Online article – 13 April 2012 – **'Staff perceptions of end-of-life care following implementation of the Liverpool Care Pathway for the dying patient in the acute care setting.'** <http://online.liebertpub.com/doi/abs/10.1089/jpm.2011.0375>

Noted in Media Watch, 25 October 2010:

- *BRITISH MEDICAL JOURNAL* | Online letter – 19 October 2010 – **'Good death for all remains distant goal.'** The [Liverpool] pathway has obvious appeal, but it has proved controversial, and reports of misuse remain disturbingly frequent. <http://www.bmj.com/content/341/bmj.c5815.extract>

'Final wish' granted as puppies born at hospice

U.K. (ENGLAND) | *Get Surrey* (Guildford) – 23 July 2012 – The final wish of a cancer sufferer was fulfilled when his dog gave birth to puppies in his ward at Princess Alice Hospice. Four of the eight puppies, which were born only two days before the death of owner ... are now seeking new homes. The puppies will be sold to raise money for the Esher hospice...http://www.getsurrey.co.uk/news/s/2117501_final_wish_granted_as_puppies_born_at_hospice

Specialist Publications (e.g., in-print and online journal articles, reports, etc.)

Expressions of loss and separation

Online memorials: The virtual as the new vernacular

BEREAVEMENT CARE | Online article – 24 July 2012 – It is argued that in the countries of the developed north west, such as the U.K., where a high proportion of the population are computer literate and are used to working with and communicating through virtual technology, such as social networking sites, the internet has been established as a normal place for remembering the dead. Remembrance is in part shaped by typical net practices and terminology, as well as by the technological possibilities of the internet, which, combined, accommodate ongoing uploading and editing of images, text, music and gifts. This gives these memorials a vibrant and dynamic contemporary character which is often expressed through colloquial idiom and popular culture, thereby representing and constituting aspects of the vernacular. Some social networking sites and more formal memorial hosts, such as commercial or charitable sites, place constraints on how online memorials are organised and what might be included, but the majority retain an emphasis on the deceased as an individual, and attempt to reflect their character, interests...
<http://www.tandfonline.com/doi/abs/10.1080/02682621.2012.710491>

Of related interest:

- *BEREAVEMENT CARE* | Online article – 24 July 2012 – **'Internet memory and life after death.'** Can the digital revolution lead to ... a sort of Internet-based immortality?
<http://www.tandfonline.com/doi/abs/10.1080/02682621.2012.710494>
- *BEREAVEMENT CARE* | Online interview – 24 July 2012 – **'Bringing alive a life that is ending.'** Filmmaker Evangelo Kioussis describes his biographical film-making project and how he feels it helps the bereaved and dying people.
<http://www.tandfonline.com/doi/abs/10.1080/02682621.2012.710496>

Noted in Media Watch, 4 June 2012:

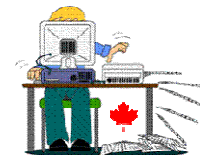
- *USA TODAY* | Online report – 30 May 2012 – **'Mourning becomes electric: Tech changes the way we grieve.'** <http://www.usatoday.com/tech/news/story/2012-05-07/digital-mourning/55268806/1>

Recognizing and treating complicated grief

CURRENT PSYCHIATRY, 2012;11(8):30-35. In this article, the authors evaluate the growing body of research on complicated grief (CG) – which also has been called prolonged grief, chronic grief, traumatic grief, and pathological grief – with an emphasis on how to identify CG and distinguish it from other adaptive and maladaptive reactions to the loss of a loved one. In addition, they review empirical evidence on treating CG, including psychotherapy, pharmacotherapy, and combined treatment approaches. The bereavement-specific syndrome we refer to as CG currently is being reviewed for possible inclusion in DSM-5 [Diagnostic and Statistical Manual of Mental Disorders] as an official diagnosis.
http://stg.currentpsychiatry.com/pdf/1108/1108CP_Simon.pdf

Barry R. Ashpole

My involvement in palliative and end-of-life care dates from 1985. As a communications specialist, I've been involved in or responsible for a broad range of initiatives at the community, regional, provincial and national level. My work focuses primarily on advocacy, capacity building and policy development in addressing issues specific to those living with a life-threatening or terminal illness – both patients and families. In recent years, I've applied my experience and knowledge to education, developing and teaching on-line and in-class courses, and facilitating issue specific workshops, for frontline care providers. Biosketch on the International Palliative Care Resource Center website at: <http://www.ipcrc.net/barry-r-ashpole.php>



Food or medicine: Ethnic variations in perceptions of advanced cancer patients and their caregivers regarding artificial hydration during the last weeks of life

BMJ SUPPORTIVE & PALLIATIVE CARE | Online article – 23 July 2012 – Artificial hydration was perceived as food/nutrition by many cancer patients and caregivers in the study, particularly among ethnic minorities. This perception may lead to greater distress if fluids are discontinued or withheld. <http://spcare.bmj.com/content/early/2012/07/23/bmjspcare-2012-000205.abstract>

Palliative care training substandard

CANADIAN MEDICAL ASSOCIATION JOURNAL | Online article – 25 July 2012 – Most of the hundreds of thousands of Canadians who die each year from natural causes spend their final days under the care of family doctors and nurses. Many experts in end-of-life care question whether these caregivers have the skills necessary to ensure dying patients meet peaceful ends, and are calling for more palliative experts and increased training for all physicians. To that end, efforts have been initiated to create a subspecialty in palliative medicine, but experts say there's still a need for more core training of all physicians about its nuances. "I think that palliative care is similar to, say, cardiology, where all physicians, all nurses and health care professionals need to have a base level of knowledge in order to manage most of the issues of patients," says Dr. Deborah Dudgeon, co-chair of the Royal College of Physicians and Surgeons of Canada and the College of Family Physicians of Canada Conjoint Advisory Committee on Palliative Medicine. "But once things get a bit more complex, then there needs to be another one or two levels of expertise that can support people so that they can get optimal care." Numerous studies have shown there are significant variations in the quality of palliative care that Canadians receive. Although studies repeatedly show that most people would prefer to die at home while receiving appropriate end-of-life care, that's generally not the norm. http://www.cmaj.ca/site/earlyreleases/25july12_palliative-care-training-substandard.xhtml

N.B. Canada was rated 9th (of the 40 countries surveyed) in *The Quality of Death: Ranking End-of-life-Care Across the World*, commissioned by the Lien Foundation, Singapore, published by the Economist Intelligence Unit, July 2010. http://graphics.eiu.com/upload/QOD_main_final_edition_Jul12_toprint.pdf

End-of-life care in rural areas: What is different?

CURRENT OPINION IN SUPPORTIVE & PALLIATIVE CARE | Online article – 15 July 2012 – This review explores global developments in palliative care ... in rural settings, since 2010. It highlights models of rural palliative care provision including challenges faced in establishing services and draws upon examples from around the world. Although culture and geography will change, challenges to providing palliative care in rural settings appear to be almost universal. Caution is raised in transplanting urban models to rural settings... http://journals.lww.com/co-supportiveandpalliativecare/Abstract/publishahead/End_of_life_care_in_rural_areas_what_is.99812.aspx

Noted in Media Watch, 2 July 2012:

- *GLOBAL JOURNAL OF HEALTH SCIENCE*, 2012;4(5):1-13. 'Canadian rural-urban differences in end-of-life care...' <http://www.ccsenet.org/journal/index.php/gjhs/article/viewFile/17521/12109>

N.B. See Media Watch, 30 April 2012 (p.8-9), for a listing of additional articles, reports, etc., on the provision and delivery of end-of-life care in the rural setting.



<http://www.worldday.org/>

October 13 2012

Neonatal end-of-life care

Three myths in end-of-life care

JOURNAL OF MEDICAL ETHICS | Online article – 25 July 2012 – Huang and colleagues¹ provide some intriguing insights into the attitudes about end of life care of practising Taiwanese neonatal doctors and nurses. There are some similarities with surveys from other parts of the world. Most Taiwanese neonatologists and nurses agreed that it was potentially appropriate to withhold or limit treatment for infants who were dying. A very high proportion was opposed to active euthanasia of such infants. But there were also some striking differences. Only 21% of Taiwanese doctors 'agreed' with withdrawal of mechanical ventilation for dying newborn infants. This proportion is lower than reported in any European country. More than 90% of neonatologists surveyed in the U.K., the U.S., The Netherlands and Sweden found withdrawal of mechanical ventilation acceptable. Taiwanese doctors also seemed reluctant to give analgesia or sedatives to such infants, with almost 60% disagreeing with their use in dying infants where there was a risk of hastening death. In contrast, two-thirds or more of European neonatologists thought this was acceptable (and in several countries this rate was again above 90%). The results of the survey of Huang *et al* highlight three beliefs about end-of-life care that are widespread, but all of which are seriously mistaken ... <http://jme.bmj.com/content/early/2012/07/24/medethics-2012-100723.extract>

1. 'The attitudes of neonatal professionals towards end-of-life decision-making for dying infants...' *Journal of Medical Ethics*, 5 May 2012. <http://jme.bmj.com/content/early/2012/05/04/medethics-2011-100428.abstract?sid=ea1ce9df-c4a5-4e29-ba2c-5aaa17c71189>

Enhancing patient-professional communication about end-of-life issues in life-limiting conditions: A critical review of the literature

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online article – 23 July 2012 – Of the 755 articles initially identified, 16 met the inclusion criteria. Three core themes emerged from the synthesis of the literature using education to enhance professional communication skills, using communication to improve patient understanding, and using communication skills to facilitate advance care planning. Evidence relating to the development and evaluation of communication interventions for patients with life-limiting illnesses would suggest that a successful intervention should include combined components of training, patient discussion, and education. In a context of limited resources and an increasing number of patients living and dying with chronic life-limiting conditions, the need for appropriate and effective communication strategies should be seen as a priority for both research and policy. [http://www.jpsmjournal.com/article/S0885-3924\(12\)00206-0/abstract](http://www.jpsmjournal.com/article/S0885-3924(12)00206-0/abstract)

Editorial

An unspoken need

BRITISH JOURNAL OF COMMUNITY NURSING, 2012;17(8):355. The phenomenon of caring for people with communication difficulties experiencing distress in palliative care settings is not fully understood. And yet, learning disabilities affects 2.5% of the population in the U.K. with numbers expected to increase annually. We are all living longer and are likely to experience the effect of aging, which sadly includes an increased risk of developing dementia with its associated symptoms such as distress resulting from memory loss, mood changes and depression. Furthermore, people with learning disabilities are more susceptible to developing life-threatening illnesses than the general population. http://eprints.hud.ac.uk/14368/1/Kirshbaumfinal_an_unspoken_need.pdf

Cont.

Of related interest:

- *CRITICAL CARE MEDICINE*, 2012;40(8):2464–2469. **'Influence of personal preferences for life-sustaining treatment on medical decision making among pediatric intensivists.'** Personal preferences [among study participants] for life-sustaining treatment were significantly associated with scenario-based responses to acceptability of withholding and withdrawal of life-sustaining treatment. http://journals.lww.com/ccmjournal/Abstract/2012/08000/Influence_of_personal_preferences_for.26.aspx
- *PALLIATIVE MEDICINE* | Online article – 24 July 2012 – **'The patient's use of metaphor within a palliative care setting: Theory, function and efficacy.'** The papers reviewed suggest that metaphoric communication allows sensitive subjects to be dealt with and provides benefits for patients. The results suggest that engaging with patients at the metaphoric level enables them to create new ways of viewing their situation and opens up the possibilities of new coping strategies. <http://pmj.sagepub.com/content/early/2012/07/20/0269216312451948.abstract>

Noted in Media Watch ('Worth Repeating'), 1 February 2012:

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE*, 1998;15(5):282-284. **'Communicating with metaphor...'** This article suggests that metaphor is a powerful and sensitive form of language that offers a range of characteristics particularly suitable for the art and the challenge of communicating with dying people. <http://ajh.sagepub.com/cgi/content/abstract/15/5/282>
- *PALLIATIVE & SUPPORTIVE CARE* | Online article – 18 July 2012 – **'The physician-patient relationship in treatment decision making at the end of life: A pilot study of cancer patients in a Southeast Asian society.'** This article is part of a ... study exploring the patient-physician dynamic on decision making among Southeast Asian palliative cancer patients. The authors explored: 1) influence of physicians; 2) the effect of symptom control and quality of life; and, 3) dynamics and communication of physicians. Patients appeared to place highest regard in both autonomy and physician input in making decisions, accompanied by an increased desire for more information. <http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=8641486>

Integrating palliative care in the intensive care unit

JOURNAL OF SUPPORTIVE ONCOLOGY | Online article – 20 July 2012 – The admission of cancer patients into intensive care units (ICUs) is on the rise. These patients are at high risk for physical and psychosocial suffering. Patients and their families often face difficult end-of-life decisions that highlight the importance of effective and empathetic communication. Palliative care teams are uniquely equipped to help care for cancer patients who are admitted to ICUs. Palliative care has the potential to improve a patient's symptoms, enhance the communication between care teams and families, and improve family-centered decision making. <http://www.sciencedirect.com/science/article/pii/S1544679412000985>

Noted in Media Watch, 9 April 2012:

- *JOURNAL OF PALLIATIVE MEDICINE* | Online article – 3 April 2012 – **'Barriers to end-of-life care in the intensive care unit: Perceptions vary by level of training, discipline, and institution.'** <http://online.liebertpub.com/doi/abs/10.1089/jpm.2011.0261>

Collaboration between the specialties in provision of end-of-life care for all in the U.K.: Reality or utopia?

INTERNATIONAL JOURNAL OF PALLIATIVE NURSING, 2012;18(7):339-347. This systematic review aims to critically appraise literature published in the U.K. to identify how specialist palliative care professionals can collaborate with other health professionals within four of the key National Service Framework areas: heart failure, chronic obstructive pulmonary disease, neurological conditions, and dementia. A limited amount of quality research was found. Thematic analysis was applied and the over-riding themes were barriers to collaboration, organizational issues, and patients' and carers' views. The review concludes that when a collaborative approach to care is used, quality end-of-life care is achieved. Each disease pathway needs greater clarity regarding how it links with the [U.K.'s] End of Life care Strategy. http://www.ijpn.co.uk/cgi-bin/go.pl/library/article.html?uid=93275;article=IJPN_18_7_339_347

Cont.

Noted in Media Watch, 21 November 2011:

- *CRITICAL CARE MEDICINE* | Online article – 10 November 2011 – **'Integrating palliative care in the surgical and trauma intensive care unit: A report from the Improving Palliative Care in the Intensive Care Unit Project Advisory Board and the Center to Advance Palliative Care.'** http://journals.lww.com/ccmjournal/Abstract/publishahead/Integrating_palliative_care_in_the_surgical_and.98189.aspx

A narrative literature review of the contribution of volunteers in end-of-life care

PALLIATIVE MEDICINE | Online article – 24 July 2012 – Sixty-eight articles were included in the analysis. The articles were drawn from an international literature, while acknowledging that volunteer roles vary considerably by organisation and/or by country and over time. The majority of articles were small in scale and diverse in methodology, but the same topics repeatedly emerged from both the qualitative and quantitative data. The themes identified were individual volunteer factors (motivation, characteristics of volunteers, stress and coping, role boundaries and value) and organisational factors (recruiting for diversity, support and training and volunteers' place in the system). <http://pmj.sagepub.com/content/early/2012/07/20/0269216312453608.abstract>

Noted In Media Watch, 23 July 2012:

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online article – 18 July 2012 – **'Holding on to what you have got: Keeping hospice palliative care volunteers volunteering.'** <http://ajh.sagepub.com/content/early/2012/07/16/1049909112453643.abstract>

Noted in Media Watch, 16 January 2012:

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online article – 12 January 2012 – **'Should I stay or should I go: A study of hospice palliative care volunteer satisfaction and retention.'** <http://ajh.sagepub.com/content/early/2012/01/04/1049909111432622.abstract>

Media Watch: Editorial Practice

Each listing in Media Watch represents a condensed version or extract of what is broadcast, posted (on the Internet) or published; in the case of a journal article, an edited version of the abstract or introductory paragraph, or an extract. Headlines are as in the original article, report, etc. There is no editorializing ... and, every attempt is made to present a balanced, representative sample of "current thinking" on any given issue or topic. The weekly report is issue-oriented and offered as a potential advocacy tool or change document.

Distribution

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Something Missed or Overlooked?

If you are aware of a current report, article, etc., relevant to hospice, palliative care or end-of-life issues not mentioned, please alert this office (contact information below) so that it can be included in a future issue of Media Watch. Thank you.

Distinguishing spiritual, psychological, and psychiatric issues in palliative care: Their overlap and differences

PROGRESS IN PALLIATIVE CARE, 2012;20(2):79-85. The authors present a four-step assessment for determining which perspective and which clinician may best aid a patient: 1) distinguish whether suffering is due to a normal syndrome of distress or to a psychiatric disorder; 2) assess the potential efficacy of spiritual care, psychotherapy, or psychopharmacology for relieving distress of this type; 3) determine probable effectiveness for spiritual care, psychotherapy, or psychopharmacology given limitations of clinician availability, clinicians' clinical competencies, and the treatment setting; and, 4) learn whether the patient has a strong preference for a consultant with a secular (psychiatrist, psychotherapist) or religious (chaplain, clergy) professional identity. This assessment prioritizes patient preferences in its decision making, while evaluating the clinical problem, consultants' capabilities, and treatment setting so that recommendations hold promise for effectiveness. Spirituality, psychology, and psychiatry are each richly developed traditions of healing. The aim of care should be to provide the best from each towards reducing a patient's suffering. <http://www.ingentaconnect.com/content/maney/ppc/2012/00000020/00000002/art00004>

N.B. This issue of *Progress in Palliative Care* includes several articles on the spiritual aspects of palliative care. Contents page: <http://www.ingentaconnect.com/content/maney/ppc/2012/00000020/00000002>

Of related interest:

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online article – 24 July 2012 – **'Outcome measures of spiritual care in palliative home care: A qualitative study.'** <http://ajh.sagepub.com/content/early/2012/07/20/1049909112454563.abstract>
- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online article – 24 July 2012 – **'Assessing somatic, psychosocial, and spiritual distress of patients with advanced cancer...'** <http://ajh.sagepub.com/content/early/2012/07/20/1049909112453640.abstract>
- *PALLIATIVE MEDICINE* | Online article – 27 July 2012 – **'Cross-cultural development of the EORTC QLQ-SWB36: A stand-alone measure of spiritual wellbeing for palliative care patients with cancer.'** The European Organisation for Research & Treatment of Cancer (EORTC) measure of spiritual wellbeing for palliative care patients with cancer ... identifies key issues for spiritual wellbeing in multiple cultural contexts, and that items are comprehensible and consistent across languages. [In this study] some cross-cultural differences were observed, but data were insufficient to enable generalisation. Phase IV field-testing will investigate these differences further. <http://pmj.sagepub.com/content/early/2012/07/20/0269216312451950.abstract>

Assisted (or facilitated) death

Representative sample of recent articles, etc:

- *JOURNAL OF THE NEW ZEALAND MEDICAL ASSOCIATION*, 2012;125(1358): **"I wouldn't want to become a nuisance under any circumstances" – A qualitative study of the reasons some healthy older individuals support medical practices that hasten death.** The authors' study provides confirmation that the fear of being a burden on others is not only felt by those facing their imminent mortality, but also by older individuals who are currently healthy and living independently in the community. We also conclude that for some older people their prior experiences with health care and dying may be a strong factor in influencing and supporting medical practices that hasten death at the end of life. They believe it is crucial to understand the reasons why people support medical practices that hasten death well in advance of such practices ever becoming legally available. <http://journal.nzma.org.nz/journal/abstract.php?id=5256>

Cont.

- **NEWS MEDICAL** | Online report – 24 July 2012 – '**Central mechanism would remove physician from assisted-dying process.**' The development of a central state or federal mechanism in the U.S. that would confirm the authenticity and eligibility of terminally ill patients' requests for death, dispense medication, and monitor demand and use, could remove physicians from the assisted dying process, say researchers. More than half of the American Medical Association members surveyed in 2003 objected to physician-assisted suicide, believing it is wrong to play an active role in ending a patients' life, explain Julian Prokopetz and Lisa Lehmann (Brigham and Women's Hospital and Harvard Medical School, Boston, Massachusetts). However, they envision that removing physicians from the process would mean they would not be required to take actions that are not already part of a commitment to providing high-quality care. <http://www.news-medical.net/news/20120724/Central-mechanism-would-remove-physician-from-assisted-dying-process.aspx>
1. 'Redefining physicians' role in assisted dying.' *New England Journal of Medicine*, 2012;367(2):97-99 (noted in Media Watch, 16 July 2012). <http://www.nejm.org/doi/full/10.1056/NEJMp1205283>

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Canada

ONTARIO | Hamilton Niagara Haldimand Brant Hospice Palliative Care Network: <http://www.hnhbhpc.net/CurrentNewsandEvents/tabid/88/Default.aspx> (Click on 'Current Issue' under 'Media Watch')

ONTARIO | HPC Consultation Services (Waterloo Region/Wellington County): <http://www.hpcconnection.ca/newsletter/inthenews.html>

ONTARIO | Mississauga Halton Palliative Care Network: <http://www.mhpcn.ca/Physicians/resources.htm?mediawatch=1>

ONTARIO | Palliative Care Consultation Program (Oakville): <http://www.palliativecareconsultation.ca/?q=mediawatch>

U.S.A.

Prison Terminal: <http://www.prisonterminal.com/news%20media%20watch.html>

Europe

HUNGARY | Hungarian Hospice Foundation: <http://www.hospicehaz.hu/en/training/> (Scroll down to 'Media Watch')

U.K. | Omega, the National Association for End of Life Care: <http://www.omega.uk.net/media-watch-hospice-palliative-care-and-end-of-life-news-n-470.htm?PHPSESSID=b623758904ba11300ff6522fd7fb9f0c>

Asia

SINGAPORE | Centre for Biomedical Ethics (CENTRES): <http://centres.sg/> (Scroll down to 'What's New: Reading List Update')

International

Australasian Palliative International Link: <http://www1.petermac.org/apli/links.htm> (Scroll down to 'Media Watch')

Palliative Care Network Community: <http://www.pcn-e.com/community/pg/file/owner/MediaWatch>

International Palliative Care Resource Center: <http://www.ipcrc.net/archive-global-palliative-care-news.php>

Barry R. Ashpole
Beamsville, Ontario CANADA

' phone: 905.563.0044
 e-mail: barryashpole@bellnet.ca